

In the Supreme Court

SEP 11 1989

JOSEPH F. SPANIOLO, JR.
CLERK**OF THE
United States**

OCTOBER TERM, 1989

LOUIS W. SULLIVAN, Secretary of Health and
Human Services,
Petitioner,

VS.

BRIAN ZEBLEY, et al.,
Respondent.

**On Writ of Certiorari to the United States Court of Appeals
For the Third Circuit**

**BRIEF OF AMICI CURIAE
THE CHILDREN'S DEFENSE FUND
THE CYSTIC FIBROSIS FOUNDATION
THE SPINA BIFIDA ASSOCIATION OF
GREATER LOS ANGELES
THE TOURETTE SYNDROME ASSOCIATION
THE REHABILITATION PRESIDENTS
COUNCIL OF CALIFORNIA
PERLA ACOSTA, KENYADA ALES, DAWN BOUCHER,
CHERYL CAUDILL, SARA CHASE, JENNIFER COX,
BLAKE DEWITT, RICHARD DOONE, YOLANDA DOWDY,
AMY GIFFORD, LAWERENCE GREATHEART,
VALERIE HARTWELL, TERRY HOUCK,
DELDRIK JACKSON, SHAWN KELLER,
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BRIEF OF AMICI CURIAE
CHILDREN'S DEFENSE FUND, ET. AL.

INTEREST OF AMICI CURIAE
THE CHILDREN'S DEFENSE FUND ("CDF") is a
national public charity representing and

providing advocacy on behalf of America's children, especially low-income, minority, and handicapped children. CDF works through litigation, public education, analysis of public policy, lobbying, and other methods to improve the care and development of children and the economic status of children and their families. CDF's experience in such work demonstrates that children with handicaps have special needs which must be met through public income support programs when family resources are inadequate and that the wrongful denial of such public assistance has a host of adverse consequences for disabled children.

THE CYSTIC FIBROSIS FOUNDATION is striving to provide a better future for people with cystic fibrosis through improved medical care and better research. Cystic fibrosis is a fatal, genetic disease. The symptoms of this disease include thick, sticky, mucus secretions that clog the lungs

and gastrointestinal system, impairing breathing and digestion. The mucus can lead to recurrent lung infections and malnutrition. Other severe complications of cystic fibrosis can include diabetes and cardiac problems. Separately, these symptoms may not meet the Social Security Administration's requirements for disability. However, when all aspects of the disease are viewed together, the combination can be extremely disabling. Currently, many children with cystic fibrosis who apply for Supplemental Security Income (SSI) are turned down because they do not meet the restrictive medical listings. Despite the devastating effect of cystic fibrosis on a child's daily life and the continuous medical treatment that may be necessary, children are ineligible for SSI benefits if their breathing impairments are not severe enough to render them totally disabled according to the respiratory

category in the Listing of Impairments. Often, the effects of the disease on other parts of the child's body are not considered, since the child's total functional capacity is not evaluated.

SKIP (Sick Kids need Involved People) NATIONAL, INC. was organized by parents in 1983 to assist individuals, especially children with their families, who have extraordinary health care needs. Through the national organization and 24 State Chapters, SKIP has touched the lives of several thousand individuals and their families. The diagnoses of these individuals varies widely, but most require life support equipment. One of the goals of SKIP is to advocate for families to receive adequate and appropriate care and services in home and community based environments.

THE SPINA BIFIDA ASSOCIATION OF GREATER LOS ANGELES includes persons with spina bifida, families of children with spina

bifida, and professionals. A significant segment of the membership includes low-income families of children with spina bifida. Many of the disability problems children with spina bifida have, and which result in functional limitations, are not catalogued in the Listing of Impairments. Unlisted factors include: gastrostomy tubes into the stomach through which a child is fed; tracheostomies which are openings into the neck through which the child breathes and through which the child is suctioned to prevent aspiration or pneumonia; and shunts to remove excess fluid from the head to prevent or minimize brain damage from the pressure of water on the brain. Because these functional limitations are not catalogued in the listings, some severely disabled children with spina bifida have not been able to qualify for SSI.

THE TOURETTE SYNDROME ASSOCIATION, INC. is the only national voluntary non-profit

membership organization dedicated to identifying the cause, finding the cure, and controlling the effects of Tourette syndrome. Tourette syndrome is a neurological disorder characterized by involuntary tics -- rapid, sudden movements that occur repeatedly in the same way. Tourette syndrome is a chronic disorder with manifestations that can prevent an individual from functioning independently and that can cause a diagnosed individual to require extended, individualized services. Nevertheless, it is not included in the Listing of Impairments established by the Social Security Administration. Youngsters with Tourette syndrome who have a high level of motor tics can experience significant impairment of their motor function that can interfere with their use of fingers, hands and arms. Drugs that are used to bring the motor symptoms under control can cause lethargy and mental dullness. The socially

unacceptable nature of certain vocal tics has precluded some children from being enrolled in standard classrooms. These symptoms, together with learning disabilities and attention deficit disorder, limit the training of these youngsters for eventual economic self-sufficiency.

THE REHABILITATION PRESIDENTS COUNCIL OF CALIFORNIA (RPCC) is a statewide consortium of professional rehabilitation associations which seeks to improve the effectiveness of rehabilitation through education and research. RPCC represents approximately 2,000 rehabilitation professionals who provide or coordinate physical and vocational rehabilitation services in California.

The following children have been denied SSI on the basis of disability. Their cases illustrate that the Secretary's procedure for determining disability in children's cases fails to take into account significant

functional impairments.

PERLA ACOSTA is two years old and lives in California. She has Down syndrome and is severely developmentally delayed. She functions in the nine to ten month level in speech and communication skills and at the fifteen to eighteen month level in other areas. Her school reports that, because of her severe delay in the area of communication, Perla can be expected to demonstrate a verbal IQ of 59 or below when she is old enough to test.

Perla has been denied SSI on the basis that she has not demonstrated a 50% delay in all areas of development as required by 20 C.F.R. Part 404, Subpart P, Appendix 1 ("Listings") §112.05A. (Determination dated January 26, 1989). Her request for reconsideration is pending.

KENYADA ALES is almost two years old and lives in Mississippi. She was born with severe hydrocephalus which occurs when

cerebrospinal fluid can't exit the brain. In Kenyada's case, a shunt was implanted to enable the excess fluid to drain from her head into her abdomen. In her first 15 months of life, Kenyada suffered three shunt failures which required hospitalization and surgical intervention. Kenyada shows signs of brain damage including developmental delays, hemiplegia, and vision problems, as well as symptoms associated with shunt problems including headaches, nonresponsiveness, and abdominal tenderness.

Kenyada has been denied SSI benefits. An Administrative Law Judge determined that her impairments do not meet or equal the childhood listings (Decision dated May 11, 1989).¹ Her case is pending before the Appeals Council.

DAWN BOUCHER is nineteen years old and

¹ All records and documents referred to are in the custody of the Secretary and have been made available to counsel for the plaintiff-respondents.

lives in Vermont. She reached majority during the time that her claim was on appeal. Therefore she is claiming child benefits for the period before she reached her eighteenth birthday and adult benefits for the period thereafter. Ms. Boucher suffers from borderline retardation but her adaptive functioning is consistent with the mild range of mental retardation. She also has learning impairments, a speech impairment, a mixed personality disorder with dependent and avoidant features, and an anxiety disorder. In addition, she suffers from depression, allergic rhinitis, headaches, and fainting spells.

The federal district court has denied Ms. Boucher's claim for child benefits but has remanded her claim for adult benefits to determine whether she can perform work that exists in the national economy. Boucher v. Bowen, No. 87-183 (D. Vermont Order dated July 20, 1988.) The court denied the claim

for child benefits on the basis that her impairments do not meet or equal the Listing of Impairments. Under current regulations, Listings, §112.05C, her adaptive functioning level and her other impairments cannot be considered because her IQ score is above 69. Boucher v. Bowen, supra, Magistrate's Report and Recommendation (June 9, 1988).

CHERYL CAUDILL is fourteen years old and lives in Kentucky. She was diagnosed as diabetic in February, 1988. Over the following year she was hospitalized several times with uncontrolled diabetes. Her hospital stays ranged from a few days to a week or more. Even when she was in the hospital, the insulin therapy was inadequate to control the diabetes. She also experienced seizure-like symptoms and emotional problems. Cheryl has been denied SSI benefits and now has an appeal pending in federal court. Caudill v. Sullivan No. 89-180 (E.D. Ky. filed July 14, 1989).

SARA CHASE is four years old and lives in Vermont. She was born with Hirschsprung's Disease, a congenital abnormality of the large bowel. By the age of three and one half months, Sara had been through two major surgeries. Since that time, she has had worsening problems of entero colitis, granuloma, severe cramping, malabsorption syndrome, and dysmotility disorder. She also experiences problems of fecal incontinence, abdominal distention, intermittent diarrhea, intermittent rectal bleeding, fissures, eating difficulties, appetite loss, and weight loss. In 1988 alone, Sara was hospitalized five times. In March of 1988, she was started on an enteral feed system by means of a naso-gastric feed tube. The feed tube must be in place 24 hours a day and is hooked up to an infusion pump at least three times.

Sara has been denied SSI twice on initial application. She is now pursuing

her case through the administrative process.

JENNIFER COX is six years old and lives in Iowa. Jennifer suffers from anorectal atresia, a congenital anomaly of the bowe', which required her to have a colostomy. Additional surgery resulted in relocation of the anus and closure of the colostomy. However, she has continuing difficulty with constipation and bowel dysfunction, and further surgery has been recommended. She currently requires daily enemas, suppositories, and adherence to a strict diet to enable her to have bowel movements. In addition, Jennifer suffers from chronic urinary tract infections and is unable to sense when her bladder is full. As a result of these problems, Jennifer is not yet toilet trained. She also suffers from Duane's syndrome, an eye muscle deficiency, which prevents her from moving her eyes to look to either side. As a result, she lacks peripheral vision. Her mother reports that

she must constantly lean sideways to see and that she runs into walls because she cannot see them.

Jennifer has been denied SSI benefits. An Administrative Law Judge determined that her impairments did not meet or equal the listings. He said that her case must be judged solely on the objective medical evidence and not on other factors, which are applicable only to adult determinations. (Decision dated December 28, 1988.)

BLAKE DEWITT is 13 years old and lives in Texas. Blake suffers from asthma, obesity, and childhood migraine. In 1981, after he began taking Prednisone, a cortisone-like anti-inflammatory medication, he began to gain weight very quickly. In 1986, his physician concluded that he was unable to engage in any strenuous activity because of congenital tracheal malasia and acute asthmatic bronchitis with chronic lung disease. Blake's blood pressure has risen

as high as 190/110, and he has suffered severe headaches, vertigo, hypertensive encephalopathy, and nose bleeds. Blake has continued to gain weight, and at the time of his hearing before an Administrative Law Judge, at age eleven, he weighed 241 pounds.

Blake was found to be disabled from June 13, 1978 through December, 1982 but has been denied SSI benefits on reapplication for benefits filed January 1, 1984. His appeal is pending in the Court of Appeals for the Fifth Circuit, DeWitt v. Sullivan, Case No. 89-5559.

RICHARD DOONE is seven years old and lives in Pennsylvania. Richard suffers from asthma, which was diagnosed in 1984. By the time his case was submitted to the Appeals Council in 1988, Richard had been hospitalized six times and had received emergency room treatment twenty times. He has been using a breathing machine for several years, and at the time of his

hearing, he was using it four times a day for one half hour each time. He is taking Slobid, Alupent, and Predatson, and has required parenteral² medication during his asthma attacks. Richard missed 67 days of his eight month preschool program during the 1986-1987 school year, and 21 out of 103 class days in kindergarten the next year.

Richard has been denied SSI. A vocational expert concluded that Richard is disabled because of the frequency of his asthma attacks and because he requires home nebulizer treatments to maintain adequate ventilation. However, the Administrative Law Judge determined that Richard did not meet the Listing of Impairments because the rate of hospitalization had decreased recently and because his medical condition between hospitalizations was not sufficiently severe. (Decision dated March

² "Parenteral" refers to medication administered by injection.

23, 1988.) Richard's case is now before the Appeals Council.

YOLANDA DOWDY is thirteen years old and lives in Pennsylvania. Yolanda is in an EMR (Educable Mentally Retarded) class at school. Although her full scale IQ is in the upper range for EMR students, her academic achievement is in the lower range. Her language development and communication skills are extremely deficient. She wets and soils herself during the day at school. At home she is unable to do age appropriate tasks such as doing the dishes and taking out the garbage. She has also exhibited antisocial behavior.

Yolanda has been denied SSI benefits. She is awaiting the outcome of her June 15, 1989 hearing on remand from the Appeals Council.

AMY GIFFORD is eight years old and lives in Vermont. She has a full scale IQ of 71, and she demonstrates significant

delays in visual-motor abilities, visual-perceptual abilities, language skills and articulation. Unlike children with mild retardation who do not have her other problems, Amy needs to be helped with self-care skills, particularly bathing, toileting, and dressing herself. She is unable to match clothing and to consistently brush her hair. Her ability to retain information is limited. She does not understand money and is not able to tell that there are five pennies in a nickel. She is unable to add simple numbers without counting on her fingers.

Amy also has a speech impairment, which, in combination with her memory difficulties make conversation difficult. She has developed some behavior problems, possibly as a result of frustration in communication. School records indicate that she also suffers from hyperactivity and inattention. She finds it difficult to stay

on task, wanders around the room, and becomes easily frustrated with lengthy problems.

Amy has been denied SSI benefits. The initial denial acknowledged that she had learning problems but concluded that her impairments were not severe enough to meet the special medical requirements for child's disability benefits (Determination dated September 19, 1988). Her case is now pending before an Administrative Law Judge.

LAWRENCE GREATHEART is almost eleven years old and lives in New York. Lawrence suffers from a severe form of asthma with numerous allergies. He requires specialized treatments in the form of inhalation therapy, asthma medications taken by mouth and by injection, a special diet, and chest physiotherapy, including chest percussion and postural drainage. He also requires humidification and air conditioning.

Lawrence was hospitalized repeatedly until his mother was able to obtain a nebulizer a few years ago. He is subject to frequent headaches and gastro-intestinal disturbances related to side effects of the medication he receives. Lawrence is unable to tolerate the public transportation system because he reacts to dust, mildew, and dirt with bronchial spasms. He can't tolerate being out in cold or damp weather for extended periods or when the pollen count is high or the air quality is poor without severe respiratory compromise. He has also been diagnosed as emotionally unstable and is undergoing weekly therapy at a mental health clinic. His school attendance is irregular, with excessive absences. He missed 53 days during the last school year. He has a decreased activity tolerance and cannot participate in most typical activities with his peers without allowing for frequent rest periods.

Lawrence and his family are living in a substandard apartment due to lack of funds. They have frequent problems with water leaks and flooding which leads to the growth of mold and mildew. Spores from the mold and mildew have triggered asthmatic reactions in Lawrence.

Lawrence has been denied SSI on initial application and reconsideration because his condition, though severe, is not disabling according to the standards for minor children.

VALERIE HARTWELL just turned 18 and lives in Vermont. She is claiming children's benefits for the period from September, 1985, when she filed her most recent claim, through her eighteenth birthday on June 25, 1989. Valerie was diagnosed as suffering from cystic fibrosis when she was five months old. She is treated with pancrease, a pancreatic supplement, to aid digestion; with a special

diet; and with chest therapy twice a day to expel the mucus that builds up in her lungs. She has had to be hospitalized frequently when her condition deteriorates, primarily due to serious respiratory complications that require parenteral antibiotic treatment. Her hospital stays last from a few days to a week or more. After discharge, she undergoes intravenous therapy at home for another week.

Ms. Hartwell has a chronic cough which causes frequent gagging and vomiting. She is particularly susceptible to colds and bronchial infections and often has to take antibiotics to avoid more serious illnesses. At age eight, she was diagnosed as suffering from asthma and allergies. As a result, she must use an inhaler four to six times a day and must take Prednisone every other day. The asthma has exacerbated the pulmonary problems caused by the cystic fibrosis, and Ms. Hartwell suffers weekly asthma attacks

which often occur at night causing her to lose sleep.

Ms. Hartwell is allergic to many substances including cigarette smoke, dust, mowed grass, strawberries, carrots, and bees. She continues to be treated for pancreatic insufficiency and to suffer gastro-intestinal distress which causes weekly diarrhea, constant gas and bloating, and frequent stomach pains. In addition, scoliosis was diagnosed in 1984. This condition causes back pain and prevents her from lifting heavy objects. She is being treated for the scoliosis with prescribed exercises and with clinical treatments; however, she finds that she cannot do the prescribed exercises consistently due to her asthma and cystic fibrosis. In 1985, diabetes was diagnosed. At the time of her hearing before the Administrative Law Judge, Ms. Hartwell was taking over 40 prescribed medications daily. Although Ms.

Hartwell was granted SSI benefits at an early age, the Secretary terminated her benefits when her condition improved. She was denied benefits twice in 1983 and again in 1985. She appealed the last denial through the administrative process and the federal court. Her claim has now been remanded for further administrative proceedings. Hartwell v. Sullivan, No. 88-74 (D. Vt. Remanded May 4, 1989).

TERRY HOUCK, is fifteen years old and lives in Wisconsin. He suffers from mental retardation, attention deficit disorder, and minimal brain dysfunction. He is taking Ritalin for hyperactivity. In addition, Terry is very aggressive, has difficulty relating to his peer group, and spends much time alone and withdrawn. He attends classes for children with learning disabilities, but finds school to be a struggle. Recently, doctors have determined that Terry suffers from scoliosis, that his

right leg is slightly longer than the left, and that he has pelvic tilt.

Terry has been denied SSI benefits and has exhausted all levels of administrative review. He is the plaintiff in a federal district court action which has been stayed pending the outcome of this case. Houck v. Sullivan, No. 88-C-1225 (E.D. Wisc. Stay entered May 24, 1989).

DELDRIK JACKSON is twelve years old and lives in New York. Deldrick has been diagnosed as severely emotionally disturbed. He has frequent violent outbursts, and has had a long history of serious disciplinary problems at home and at school. He has been physically and verbally aggressive with little provocation and has been placed in increasingly restrictive special education classes at school.

Deldrick has been denied SSI benefits. An Administrative Law Judge determined that his impairments do not meet or equal the

listings. (Decision dated July, 24 1989). At the hearing, the medical advisor agreed that, if Deldrick were an adult, his problems with concentration, persistence, and pace, alone would prevent his employment at any job. However, the Administrative Law Judge found Deldrick ineligible for benefits because the medical findings did not meet the requirements of the listings.

SHAWN KELLER is eleven years old and lives in Pennsylvania. Shawn suffers from attention deficit disorder; with hyperactivity, mental retardation, learning problems, and a slight speech impediment. His intellectual development has been measured within the borderline range, with a Verbal Score of 70, a Performance Score of 77, and a Full Scale Score of 72. Shawn has demonstrated a delay in visual-motor coordination and low psycholinguistic abilities. He attends EMR special education classes, and despite compliance with a

medication regimen, Shawn has periods of increased hyperactivity when his classroom behavior is unacceptable. He has a short attention span, has difficulty in following directions, and requires one-on-one attention to keep on task.

Shawn has been denied SSI benefits. The Administrative Law Judge found that Shawn did not meet the listings because his lowest IQ score (70) was above the level required by the listings (69). Listings, §112.05C. He also found that the attention deficit disorder did not meet the level of severity required by the listings. (Decision dated November 29, 1988.) Shawn's case is appending before the Appeals Council.

HENRY ROSADO is eleven years old and lives in Pennsylvania. His primary language is Spanish. He suffers from mental retardation, although his IQ scores range from 40 to 78 on different tests. He also

has a visual-motor dysfunction, an oppositional disorder, and attention deficit disorder. Henry takes Ritalin to control his hyperactivity but still experiences difficulty in concentrating and in completing tasks in a timely manner. He has little tolerance for frustration, which results in either impulsive behavior or resignation of effort. In addition, Henry has marked difficulty in social functioning both within his family and with peers or teachers.

Henry has been denied SSI benefits. He appealed the initial denial through the administrative process. His case was remanded from the Appeals Council to an Administrative Law Judge who denied benefits again. Citing evidence that Henry's low IQ scores may have been the result of his passive-aggressive attitude and lack of verbal facility in English, the Administrative Law Judge found that Henry's

IQ did not meet the listings criteria. He also found Henry's oppositional disorder not to be severe. (Decision dated March 28, 1989.)

MONISHA SMITH is ten months old and lives in California. She has spina bifida myelomeningocele. She was born with a sac which contained her spinal cord and its enveloping membranes protruding from her spine. This sac was repaired and covered immediately after her birth. A shunt was implanted to drain cerebrospinal fluid from the brain down into the abdominal cavity. She has experienced one shunt failure which required surgery. The spina bifida has resulted in some paralysis which affects her legs so that she is not yet able to crawl. The paralysis has also affected her bowel and bladder, and as a result, Monisha requires digital stool removal and catheterization every two hours.

Monisha is developmentally delayed in

all areas. She receives occupational therapy in her home twice a week, and in the interim, her mother implements an infant stimulation program. In addition, her complex of problems requires visits to doctors at least once a week. Monica's mother, a single parent, has not been able to return to work because of the care that Monica requires.

Monisha has been denied SSI. She does not meet the listings for congenital abnormalities, because spina bifida is compatible with life outside the womb and because she can be expected to function above the two year old level. Listings, §110.08. She does not meet the neurological listings, because her paralysis has not yet interfered with age appropriate activities. Listings, §111.08A. She does not meet the listing for mental disorders because she cannot demonstrate a delay of 50% or more in all areas of development. Listings,

§112.05A.

JEANNETTE TOOMEY is five years old and lives in Pennsylvania. Jeannette suffers from severe hyperactivity, a mild expressive speech delay, and delayed fine motor skills. Although she receives an unusually high dose of Ritalin, she manifests unmanageable, disruptive, impulsive, and hyperactive behavior. In fact, the Administrative Law Judge commented on her uncontrolled behavior on the day of her hearing when she left her chair, climbed under the examining table, moved constantly about the room, and set off a fire alarm. Nevertheless, Jeannette has been denied SSI benefits. The Administrative Law Judge found clear evidence that she suffers from psychological impairments and behavior problems, but he concluded that these impairments did not satisfy the criteria of the listings. (Decision dated February 15, 1989.)

KENDRA WHALON is two years old and

lives in Texas. She suffers from Klippel-Trenaunay-Weber syndrome, a rare condition that produces a crippling growth disturbance on her left side. Her left arm is now twice the size of her right arm and colored with a birthmark-like stain. When she was 13 months old, her treating physician concluded that the condition will worsen with time, causing functional motor impairment, reduction in mobility and possible respiratory difficulties. At that point, the impairment had caused spinal curvature and loss of lung volume. In 1988, a consulting neurologist noted that Kendra was not able to use her arm at all before she started to receive physical therapy. He concluded that Kendra's overall prognosis is not good because the arm will keep growing enormously in size. He also indicated that surgery may be necessary in the future.

Kendra has been denied SSI benefits, and her case is now pending at the Appeals

Council. In denying her initial claim, the evaluator noted that Kendra may need special care and continued doctor's treatment but concluded that she was still too young to evaluate developmentally. (Determination dated December 14, 1987.) The Administrative Law Judge also found no doubt that Kendra will need regular medical care but concluded that because of the lack of findings at the listings level, he could not make a finding that she was disabled. (Decision dated November 29, 1988).

SUMMARY OF ARGUMENT

Congress extended SSI benefits to children in 1974 in order to provide a greater level of support to those in the greatest need - children with disabilities who live in poverty. Since that time, SSI has been an essential source of support for many children with disabilities and their families. However, not all children with seriously disabling conditions have been able to benefit from this program.

In this case, the Court of Appeals held that the Secretary's procedure for determining disability in children's cases violates the Social Security Act because it does not permit children to show that they suffer from any disability of comparable severity to one that would qualify an adult for SSI benefits. The Secretary's procedure is deficient because it does not provide children with the opportunity, which the Secretary provides to adults, to demonstrate

the impact that their impairments have on their ability to function.

The cases described by Amici illustrate how this limited procedure ignores seriously disabling impairments. The Secretary's procedure requires children to show medical impairments that meet or are equal to the Listing of Impairments developed by the Secretary. The procedure does not consider the actual effect the impairments have on individual children. Furthermore, it disregards significant disability factors such as dependence on medical technology or absence from school and fails to consider the actual degree of support a child may require.

Improving the Listing of Impairments will not fully resolve these problems because no medical listing can incorporate individual differences in each child's actual ability to function.

ARGUMENT

I. THE SSI PROGRAM PROVIDES ESSENTIAL SUPPORT TO CHILDREN WITH SPECIAL NEEDS.

In 1974 Congress extended the benefits of the SSI program to children to provide a greater level of support than was available at that time to children in the Aid to Families with Dependent Children (AFDC) program. The report issued by the House Committee on Ways and Means says:

It is your committee's belief that disabled children who live in low-income households are certainly among the most disadvantaged of all Americans and that they are deserving of special assistance in order to help them become self-supporting members of our society.

Making it possible for disabled children to get benefits under this program, if it is to their advantage, rather than under the programs for families with children, would be appropriate because their needs are often greater than those of non-disabled children.

House Report No. 92-231, 92d Cong., 2d Sess., pp. 147-8, reprinted in 1972 U.S. Code Cong. & Adm. News 4989, 5133-34.

Since that time, the SSI program has been an essential source of support to many children with disabilities and their families. A study commissioned by the Secretary concluded that the benefits available through the SSI program are important in meeting the significant costs of caring for a child with disabilities. Urban Systems Research & Engineering, Inc., Survey of Blind and Disabled Children Receiving Supplemental Security Income Benefits, SSA Publication No. 13-11728, 65-67 (1980). ("Survey"). In many cases, the SSI program is the only source of support for children with disabilities because it provides benefits to children in intact families who would not have been eligible for AFDC.³ Id. Even for children who are

³ In order to be eligible for AFDC, children must be deprived of parental support and care because of the death, continued absence, incapacity, or, in some states, unemployment of a parent. 42 U.S.C. §606 (a). Because "unemployment" is defined

eligible for AFDC, the higher SSI benefits are important in meeting out-of-pocket costs and the medical expenses not covered by the medicaid program. Id. 63-64.

The high cost of caring for a child with disabilities has been confirmed by other researchers. See, e.g., J. Butler, P. Buddetti, M. McManus, S. Stenmark, P. Newacheck, Health Care Expenditures for Children with Chronic Illness, in ISSUES IN THE CARE OF CHILDREN WITH CHRONIC ILLNESS, 827 - 863 (N. Hobbs, J. Perrin, eds. 1985). In the case of children with spina bifida, out-of-pocket expenses directly attributed to the child's condition have been estimated to average 12.3 percent of family income. Id. at 876. Children with cystic fibrosis often require nonprescription medications, physical therapy, extra food and nutritional

stringently, many children in intact families are not eligible for AFDC even if neither parent is employed.

supplements, and equipment for lung care, such as nebulizers, and mechanical chest percussors. N. Lewiston, Cystic Fibrosis, in ISSUES IN THE CARE OF CHILDREN WITH CHRONIC ILLNESS, supra, 201-203. Children with diabetes need more expensive food to meet special dietary needs. Children with certain mental impairments and those who are dependent on medical technology need constant or frequent protective supervision and monitoring. In many families, the parents' ability to work is limited because of the extraordinary time demands involved in providing supervision or special treatment. See e.g., D. Salkever, Parental Opportunity Costs and Other Economic Costs of Children's Conditions, in ISSUES IN THE CARE OF CHILDREN WITH CHRONIC ILLNESS, supra. 864-879. Even the expense of transportation to and from the hospital and the offices of various doctors and therapists becomes significant to families

with limited financial resources. Furthermore, many medical insurance programs require families to make co-payments for out patient services and drugs.

Children with disabilities are also more likely to be harmed by poor living conditions than are children without impairments. Substandard housing, lack of heat, inadequate nutrition, and other effects of poverty often have a serious effect on already vulnerable children. Furthermore, utility services may be critical to children with special needs. For example, the need for a regulated temperature or for special equipment not only makes utility service essential but also results in high utility bills.

In addition to the cash SSI provides to many low income children and their families, SSI eligibility may be necessary to

establish eligibility for medicaid,⁴ home health services, and other supportive programs in many states. Thus, SSI is essential to meet the special needs of children with disabilities who live in low income households. However, many needy children with severe impairments are denied the benefits of SSI.

II. THE SECRETARY'S METHODOLOGY FOR DETERMINING DISABILITY IN CHILDREN'S CASES IS UNDULY RESTRICTIVE IN THAT IT EXCLUDES CHILDREN WITH SERIOUS DISABLING IMPAIRMENTS WITHOUT PROVIDING THEM AN OPPORTUNITY TO DEMONSTRATE THEIR ACTUAL DEGREE OF FUNCTIONAL LIMITATION.

SSI benefits are available to adults and children who meet the SSI financial criteria and who are disabled. 42 U.S.C. §1381. An adult is disabled if he or she

is unable to engage in any substantial gainful activity by reason of any medically determinable physical or

⁴ States must provide medicaid benefits to children who are on SSI, 42 U.S.C. §1396a(a)(10)(A)(i), but have the option of providing these benefits to many other needy children. 42 U.S.C. § 1396a(a)(10)(A)(ii).

mental impairment which can be expected to result in death or which has lasted or can be expected to last for a continuous period of not less than twelve months.

42 U.S.C. §1382c(a)(3)(A). Children are disabled if they suffer "from any medically determinable physical or mental impairment of comparable severity." Id.

The Court of Appeals for the Third Circuit held that the Secretary's procedure denies children the opportunity to show that they suffer from any impairment of comparable severity to an impairment that would be considered disabling in an adult. Zebley v. Bowen, 855 F. 2d 67 (3rd Cir. 1988). The inquiry for children is limited to whether there are medical findings establishing an impairment that meets or is equivalent to the Listing of Impairments developed by the Secretary. Id. 74. Adults who do not meet this listings requirement are permitted to demonstrate that they are, nevertheless, disabled based on their actual

degree of functional impairment. Id. 73 Children are denied this opportunity to prove disability. Therefore, the Court of Appeals held, the Secretary's regulations are inconsistent with the statute "in precluding a finding that a child is disabled unless his impairment meets or equals a listed one." Id., 73-74.

The experience of Amici illustrates the effect of the Secretary's failure to consider a child's actual degree of functional impairment. Many children who should be found eligible are excluded from the SSI program because their particular impairment or combination of impairments do not mesh with the listings.

A. The Secretary's Procedure Fails to Take Into Account Significant Disabling Conditions.

The Listing of Impairments does not include factors that are common to many impairments, such as pain, reduced stamina, and the side effects of medication. In

adults, these factors are considered in making the assessment of residual functional capacity. However, that consideration is denied to children.⁵ Therefore, factors such as the pain caused by Blake DeWitt's migraine headaches, the discomfort resulting from Valerie Hartwell's gastro-intestinal problems, and the lack of stamina suffered by Blake and by Lawrence Greatheart is ignored.

Moreover, the Listing of Impairments does not address the symptoms that accompany many conditions, such as Tourette syndrome, attention deficit disorder, Down syndrome, or cystic fibrosis,⁶ even though these conditions require intensive support and

⁵ Congress underscored the importance of an individualized assessment of pain in enacting the Disability Amendments of 1984, Pub. L. 98-240, 42 U.S.C. § 1382c(a)(3)(g), incorporating §423(d)(5)(A).

⁶ The listings for cystic fibrosis cover only the respiratory symptoms. See, Listings, §103B.

intervention. As a result, children with these conditions must demonstrate that their impairments are equivalent to a listed impairment. However, the Secretary's definition of medical equivalence is extremely restrictive. Social Security Ruling (SSR) 83-19, J.A., 236, 238-240; Social Security Administration (SSA), Policy Operations Manual System (POMS), §24505.015, J.A. 244, 246-251. It expressly precludes any consideration of an actual functional limitation, SSR 83-19, supra, 239-240; POMS, supra, 251.

Lawrence Greatheart's case demonstrates the problems with the Secretary's methodology. The listings do not include allergies and do not provide a means for considering the functional impact of Lawrence's allergies. Therefore, the decisionmakers cannot take into account that Lawrence's allergies preclude him from using public transportation and prevent him from

going outside on many days. The effect of his medications and of his emotional problems are also disregarded. Valerie Hartwell's allergies and her susceptibility to bronchial infections are also excluded from consideration. Kendra Whalon's rare condition is not close enough to any of the listings to permit an adequate comparison.

Blake DeWitt's case demonstrates the inflexibility of the Secretary's procedure. Blake was denied benefits because he was unable to show that his hypertension caused impaired renal functioning, cerebrovascular damage or congestive heart failure, Listings §104.03, even though it frequently exceeded the level established by the child listings. His frequent headaches, dizzy spells, and nosebleeds are not taken into account to determine whether the combination of these impairments equal the listings. Blake is further disadvantaged by the fact that there is no childhood listing for obesity. The

Administrative Law Judge was required to use the adult listing for obesity which is clearly inappropriate because a child's bone structure is different from the bone structure of an adult. Blake was not found to be obese, even though his height, at 64 1/2 inches tall, was slightly below that of an average eleven year old but his weight, at 241 pounds, was more than three and a half times that of an average eleven year old at the time of his hearing.

Jeannette Toomey's case provides another illustration. Despite clear documentary evidence, supported by observations at the hearing, that Jeannette's behavior was out of control, the Administrative Law Judge felt constrained to deny benefits. As the medical advisor commented in his testimony, Jeannette's condition falls "through the cracks" in the listings. Toomey Decision, supra, 4.

Children with retardation are

particularly susceptible to falling through the cracks. When retardation is accompanied by another impairment, the additional impairments are not considered in combination unless the child's IQ score falls below 69, regardless of ability to function. Listings, §112.05C. For example, Yolanda Dowdy's severe cognitive impairments were not considered because her IQ scores fell above 69, even though her functioning, in the lower end of the EMR range, would equate to an IQ substantially below 69. Thus, Yolanda had to show that she had impairments, other than her cognitive impairments, that met or equaled a listing.

The cases of Amy Gifford, Terry Houck, Shawn Keller, and Henry Rosado present similar problems. Because their IQ scores were above 69, the impact of their impairments on their actual ability to function is irrelevant. Amy's learning disabilities reduce her ability to function

to a level well below that of a child with mild retardation alone. Terry's behavior and attention problems also reduce his ability to function. However, the IQ scores of these children prevent consideration of the overall effect of all of their impairments. In Shawn's case, the medical advisor agreed that the one point difference between Shawn's lowest score (70) and the listing requirement (69) was not meaningful, but Shawn was found not to meet the listings nevertheless. Therefore the combination of his impairments were not considered. In Henry's case, his behavioral problems and his limited knowledge of English were used to discount the IQ scores that fell below 69, rather than as evidence of impaired functioning.

Ms. Boucher's case demonstrates the difference between the treatment of children and adults. She was found not to meet the listings as a child because her IQ scores

were above 69, but as an adult, she is entitled to an assessment of her ability to do work in the national economy. This assessment will take into account the fact that she functions at a lower intellectual level than she tests.

Very young children cannot be tested for IQ. As a result, they must show a 50% delay in all areas of development. Listings, §112.05A. However, this measurement imposes an even more stringent test than does the IQ requirement. The requirement of a 50% delay is analogous to requiring a 50 IQ in mental functioning. Older children need only show an IQ score at or below 59 to qualify. In addition, older children with an IQ score between 60 and 69 may qualify by showing an additional mental or physical impairment. However, young children must show a 50% delay in all areas. Perla Acosta's case illustrates the harshness of this limitation. Even though

her developmental delay is clearly severe, she will not be able to demonstrate that she meets the listings until she is older. Monisha Smith has also been unable to demonstrate a 50% delay in all areas, despite the obvious severity of her impairments.

B. The Secretary's Procedure Fails to Take Into Account Significant Disabling Factors.

The listings do not take into account such things as dependence on medical technology, degree of support required, and absence from school. Consequently, these factors are not considered in making disability determinations for children.

Advances in medical technology have saved the lives of many children and allow many children who were once confined to institutional settings to live at home. Office of Technology Assessment Task Force, TECHNOLOGY-DEPENDENT CHILDREN: HOSPITAL VS. HOME CARE, 5 (1988), and Newacheck, Fox, &

McManus, Home Care Needs of Chronically Ill Children, CARING, (June, 1988). However, the Secretary does not take into consideration a child's dependence on this technology when determining disability.

For example, the listings do not consider tracheostomies. Tracheostomies are surgical openings in the neck through which a child breathes and through which liquids are suctioned (extracted) to prevent aspiration or formation of mucous plugs which could cut off breathing.⁷ Tracheostomies impose significant limitations on the activities of daily living, and a child with a tracheostomy usually requires supportive help at home.⁸

⁷ The frequency of the need for suctioning varies from as often as every five to ten minutes to once every other hour.

⁸ Having a tracheostomy is one of the indices of a need for skilled nursing care. 42 C.F.R. §409.33(b)(3). See, also, 42 C.F.R. §440.170 (d) incorporating §440.40 and §§409.31 through 409.35.

Most children with tracheostomies have to be closely monitored to identify the need for intervention. They also usually require pulmonary toileting.⁹ Because a child with a tracheostomy does not have the advantage of a nose to moisten air and trap dust, there are environmental limitations on where the child can go and what he can do.

The listings also do not include a range of feeding problems children experience. Because of problems in swallowing, problems with esophagus peristalsis, and problems with reflux and the aspiration of food and fluids into the lungs, many children require specialized assistance in order to receive nutrition.

⁹ Pulmonary toileting is a procedure which involves placing the child in a downward slant and percussing each of the eight lung lobes to loosen secretions. The need for pulmonary toileting varies from once or twice a day to every three hours. Failure to provide proper pulmonary toileting and timely suctioning can result in aspiration pneumonia.

This assistance may take the form of a gastrostomy (where a tube is surgically implanted in the stomach), a nasal-gastric tube, or a specific feeding protocol.¹⁰ Feeding with a nasal-gastric tube, such as that required by Sara Chase, requires the insertion of a tube through the nose, down the throat, and into the stomach. This creates a need for extensive support and presents obvious functional limitations.¹¹ Even greater than the number of children who are dependent on medical technology, is the number of children who require extensive

¹⁰ Children who require specific feeding protocols have to be fed slowly and carefully over a period of time, often taking an hour and a half or more per feeding. After feeding, they typically have to be positioned correctly to minimize the risk of food refluxing from the stomach up into the lungs.

¹¹ Having a gastrostomy or needing a nasal-gastric tube for feeding is also one of the indices of the need for skilled nursing care. 42 C.F.R. §409.33(b)(2). See note 8 above.

care at home. Newacheck, Fox, & McManus, supra. One study found that among children with significant functional limitations, help from another person was the most common type of assistance required, Id., 8. However, the Secretary does not take the need for such support into consideration in making disability determinations for children.

For example, the shunts required by Kenyada Ales and Monisha Smith impose extra care responsibilities on the family, including daily measurements of the head, monitoring of temperature to detect a shunt infection, and monitoring for nausea and changes in behavior, which indicate a shunt failure. Monisha's mother also provides daily infant stimulation therapy. Valerie Hartwell requires extensive support to provide chest therapy, to perform pinprick blood tests for diabetes four times a day, to administer insulin injections twice

daily, to administer 40 types of medication daily, to adjust her diet, and to monitor her for signs and symptoms that indicate the need for medical intervention. Jennifer Cox's mother must manage Jennifer's diet, administer daily enemas, monitor Jennifer's bladder activity closely to avoid infection, and change her several times a day because of Jennifer's inability to regulate her bladder and bowels. However, the need for extensive support is not considered in determining whether these children are entitled to receive SSI.

Some children require considerable supervision because of their behavior. For example, Jeannette Toomey and Deldrick Jackson need close supervision to attend to school work or to avoid getting into difficulty. However, this need for supervision is not part of the disability determination.

Neither is frequent hospitalization

considered, even when it significantly interferes with school. For example, Sara Chase was hospitalized five times in 1988, and Kenyada Ales has been hospitalized for surgery three times in the 22 months she has been alive. Richard Doone and Cheryl Caudill missed a significant amount of school as a result of hospitalization and other medical intervention. However, these factors are not taken into account. Richard Doone's need for four to six half hour treatments every day is also ignored.

These examples illustrate the problems that result from the Secretary's requirement that children meet or equal the Listing of Impairments. The Secretary has recently made an effort to improve the listings, but even improved listings will not compensate for the failure to provide children with an opportunity to prove their actual degree of functional limitation.

C. Improvement of the Listing of Impairments Will Not Provide Children With an Adequate Opportunity to Demonstrate Disability.

The Secretary has proposed regulations that would substantially revise the Listing of Impairments for Mental Disorders. 54 Fed. Reg. 33,238 (August 14, 1989). These regulations, if promulgated, will improve the Secretary's determination process for children with mental disorders. This improvement is important because the listings permit preliminary screening without the need for a full individualized assessment in the case of individuals whose impairments meet or equal the listings. Bowen v. City of New York, 476 U.S. 467, 470 (1986); Bowen v. Yuckert, ____ U.S. ____, 107 U.S. 2287, 2297 (1987). However, the proposed regulations do not address problems with the listings for physical impairments. Furthermore, even improved listings will not fully address the need for an individualized

assessment of functioning. See, Mental Health Association of Minnesota v. Schweiker, 554 F. Supp. 157, aff'd, 720 F. 2d 965 (8th Cir. 1983); Bowen v. City of New York, supra.

As the Secretary has recognized "[n]ot all children's impairments will lend themselves to formal codification." SSI Disability Insurance Letter No. III-11, Supp. 1 (January 9, 1974), J.A., 97. Furthermore, new and unforeseen problems,¹² developments in medicine, and differences in medical judgment will continue to make any set of medical listings inadequate as the sole criterion for determining disability.¹³ More importantly, even the most thorough

¹² For example, we are just beginning to appreciate the magnitude of the problems caused by prenatal drug exposure.

¹³ The Secretary explicitly recognized these problems in his discussion of behavioral and learning disorders. SSA Disability Insurance Letter No. III-11-Supplement 1, supra, J.A., 97-98.

listing of medical impairments⁷ will not provide an individualized assessment that considers how each child's impairments interfere with age appropriate activities of daily living, including the amount of support and intervention the child requires in order to perform those activities.

Thus, no rigid listing of medical impairments can replace the individualized assessment of a child's ability to function. Rather, the Secretary must give children the same opportunity to prove the existence of a disabling impairment that he provides to adults.

CONCLUSION

The foregoing demonstrates that the Court of Appeals was correct in holding that the Secretary's procedure denies children the opportunity to prove that they suffer from an impairment that is of comparable severity to an impairment that would be found to be disabling in an adult. This Court should uphold the decision of the Court of Appeals for the Third Circuit in this case.

Respectfully
Submitted,

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September 7, 1989